

# On Publishing the Unpublishable

Kaustubh G. Joshi, MD, and Richard L. Frierson, MD

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Medical writing comes in many forms: textbooks, peer-reviewed articles, research reports, literature reviews, practice guidelines, editorials, and case reports. Publishing affords the medical community opportunities to make important points, provoke debate, educate each other and the general public, and improve clinical (and forensic) practice.<sup>1</sup> Case reports, in particular, have been an integral component of the medical literature throughout history, with the earliest case report written around 1600 B.C. on Egyptian papyrus.<sup>2</sup> Case reports are usually based on clinical scenarios that are not frequently encountered or are novel. Consequently, there is usually a dearth of available information in the medical literature about the specific topic or clinical presentation that a case report addresses. Case reports typically involve a review of the medical literature on a subject, presentation of a relevant case, and discussion that adds to understanding of the condition or clinical situation. However, in the age of evidence-based medicine and the rising importance of journal impact factors, the publication of case reports has lost some of its luster. As a result, many journals have stopped publishing them as a matter of policy or have imposed rigorous criteria for a case report to be accepted for publication (e.g., exceptional interest, relevance, and novelty).<sup>3</sup>

Case reports have several merits over other forms of medical writing: describing novel occurrences, generating hypotheses, pharmacovigilance (e.g., identifying previously unreported complications or side effects from pharmacotherapy), utility when

other research designs cannot be implemented, and educational value in dealing with unusual presentations or clinical scenarios.<sup>4</sup> However, case reports also have limitations: lack of generalizability, difficulty in establishing cause–effect relationships, danger of overinterpretation, distraction of the reader from more germane medical topics by focusing on the unusual, and publication bias (i.e., giving the topic more attention than it deserves, simply by having published it).<sup>4</sup> Another major concern in the publishing of case reports is the protection of patients' privacy, so that the risk of identifying a subject on whom the case report is written is infinitesimal. One survey of case reports revealed evidence that medical websites that offer case reports display persistent inattention to subjects' confidentiality by not providing safeguards for subjects' information and not obtaining adequate consent from subjects before publishing potentially identifiable information.<sup>5</sup>

## Consent for Case Reports

In an effort to reduce the risk of publishing identifying information, some print journals and institutional review boards require authors to obtain informed consent from patients, regardless of whether they could be identified in a case report publication. However, this requirement, in some situations, may be so restrictive that it results in missed opportunities to learn. Although attaining consent is ideal for publishing a case report, there are situations in forensic practice where obtaining informed consent from subjects may not be practical or possible, such as when publishing a case report based on a forensic evaluation for capacity to stand trial in a criminal trial where the defendant may not be competent to give such consent. Also, there is an artificial barrier created when conducting such evaluations: defendants often view court-appointed evaluations with

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Dr. Joshi is Associate Professor of Clinical Psychiatry, and Assistant Program Director, and Dr. Frierson is Alexander G. Donald Professor of Clinical Psychiatry and Vice Chair for Education and Program Director, Forensic Psychiatry Fellowship, Department of Neuropsychiatry and Behavioral Science, University of South Carolina School of Medicine, Columbia, SC. Address correspondence to: Richard Frierson, 3555 Harden Street Ext., Suite 301, Columbia, SC 29203. E-mail: richard.frierson@uscmed.sc.edu.

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appropriate suspicion of the courts' motives and may not always agree to consent. Defendants are often concerned that the information they reveal during these evaluations could be used against them, despite disclosure by the evaluators that the information cannot be used to prove guilt. Informed consent may also be difficult to obtain for publishing a case report when the information that is to be published is unflattering to the criminal defendant or a party in civil litigation. If informed consent is always required for publication of a case report, it is likely that many case reports involving important forensic issues (e.g., cases involving kleptomania, pyromania, sexual sadistic disorder, pedophilic disorder and other paraphilic disorders, and antisocial personality disorder) would never be published.

A brief example of such a situation that the authors recently encountered and that has been reported elsewhere is as follows:<sup>6</sup>

During court-ordered evaluation of capacity to stand trial and criminal responsibility, a defendant related a history of numerous events in his life which appeared unusual to the point of being unbelievable. For example, the defendant claimed that he was kidnapped by a nefarious organization when he was a child and that he was eventually rescued and his family placed in the witness protection program. He also claimed that he directly witnessed a relative kill himself by shooting himself in the head. Collateral information revealed that these claims were untrue and that he had never been kidnapped or placed in a witness protection program. Although the relative died by suicide, the defendant did not witness the shooting.

He also exaggerated his accomplishments, reporting that he had graduated from a prestigious high school and made the highest score possible on the Armed Services Vocational Aptitude Battery (ASVAB). He stated that he was a Nuclear, Biological, and Chemical Operations Specialist in the military and later became a member of numerous Army Special Forces (Delta Forces, Green Beret, and part of Black Operations). He falsely alleged that he was in situations where he saw people being killed in combat. Once again, collateral information indicated that he did not graduate from high school, but he did obtain a GED. He was not involved in active combat and was not in Special Forces, but he did score very high on the ASVAB and was a Nuclear, Biological, and Chemical Operations Specialist.

The defendant also reported that he started a construction-related contracting company with nine employees and that his current legal charges resulted in a loss of his company's several-million-dollar signed contract with a local university. A family member stated that the defendant did not start a construction-related contracting company. After leaving the military, he worked for a similar company for several years until they went out of business. He had not served time in prison or jail.

During his forensic evaluation, the examiners initially had great difficulty deciding if the defendant had a delusional disorder or *pseudologia fantastica*, a condition involving the purposeful and seemingly compulsive telling of lies that serve no obvious secondary purpose (i.e., they do not always benefit the liar). The differentiation between delusional disorder and *pseudologia fantastica* could have a significant impact on the determination of this defendant's capacity to stand trial.

Through a complicated evaluation process, which cannot be repeated here without a fuller divulgence of the defendant's thinking in a manner that would require the defendant's consent for publication in this journal, it was determined that the defendant's presentation was most consistent with *pseudologia fantastica*, a condition that may affect the assessment of a defendant's rational ability to consult with an attorney and the evaluation of criminal responsibility. After a painstaking evaluation process, it was opined that this defendant was able to consult with his attorney, but the rationale supporting this conclusion had to be explained in detail to the attorneys and the court.

Because of the rarity of this presentation, the complexity of the required evaluation process, and the lack of medical literature that specifically addresses how *pseudologia fantastica* could affect the capacity to stand trial and the methods to be used in reaching a conclusion on that question, we decided that this case would make a useful case report. However, some journals, in which publishing such a case report might reach an audience that would find it most useful (including this Journal), generally require signed permission from the criminal defendant before submission for consideration of publication if information in the case report is not available and accessible in the public domain. However, not all journals take this position.<sup>6</sup>

There are several obstacles that this position creates in furthering the medical literature via a case report. One of the first obstacles is that a defendant may not be physically available after the forensic evaluation is completed. Therefore, obtaining written informed consent may not be practical or feasible. A second obstacle is that there is potential for the unintended implication to the defendant that publication of the case report may have a positive impact for the defendant in adjudication. The defendant may believe that consenting to publication will assist in sentence determination in a way that leads to sentence reduction, similar to concerns that prison inmates may believe that their participation in a research project during their incarceration will lessen their sentence, despite being advised otherwise during the informed-consent process. Therefore, in such

a situation, the voluntariness of the informed consent to publish could be called into question. It could also be difficult to convince the defendant that the authors of a case report are attempting to benefit the medical or forensic community with information that the defendant has provided when the defendant is more concerned about being found guilty and sentenced. For these reasons, we believe that publication of forensic case reports should never occur before adjudication.

Another major obstacle, particularly for forensic psychiatry case reports, is that the information that is to be published may not be very flattering to the defendant. In many forensic cases, it may even be pejorative and humiliating. For example, in the aforementioned case example involving *pseudologia fantastica*, it is noteworthy that *pseudologia fantastica* is also commonly referred to as “pathological lying.”<sup>7</sup> We believe it is unlikely that a defendant would want to be called a pathological liar and then consent to have the rest of the world read about it. It is also unlikely that criminal defendants, in general, would want negative information written about them, especially if it contains a report of criminal or otherwise bad behavior.

One of the authors (R.L.F.) has published a forensic case report in this Journal for which consent was obtained from a criminal defendant.<sup>8</sup> At the time, the Journal did not have a standard consent form for such a case report, and one had to be fashioned by the author. The consent form was developed based on one that had been in use by the *British Medical Journal*. We have also published a case report where consent was not obtained, but all information was taken from public sources.<sup>9</sup> However, forensic case reports raise an important question: is it ever ethical to publish a forensic case report in circumstances where informed consent from the defendant was not obtained? If not, forensic psychiatrists, perhaps more than physicians in any other medical specialty, may find it challenging to author or find relevant case reports involving novel and difficult forensic presentations that could assist in current or future forensic evaluations.

### Ethics Concerns

The American Academy of Psychiatry and the Law (AAPL) has created Ethics Guidelines for the Practice of Forensic Psychiatry which are intended to minimize complications, conflicts, misunderstand-

ings, and abuses.<sup>10</sup> According to these Guidelines, because of the competing duties to the individual and to society, forensic psychiatrists should be bound by several principles of ethics: respect for persons, honesty and striving for objectivity, justice, and social responsibility.<sup>10</sup> Respect for persons includes the right to privacy and maintenance of confidentiality, such as informing evaluatees about what evaluators will do with the information obtained during a forensic evaluation and ensuring that disclosure of this information is restricted accordingly. Respect for persons also includes obtaining consent from forensic evaluatees whenever possible. Although not mentioned in the guidelines, publishing a case report with information gathered from an evaluation without the evaluatee’s consent could certainly be viewed as a violation of the principle of respect for persons, as the evaluatee was not explicitly informed that the information disclosed could be printed in the medical literature. Respect for persons also involves preserving the dignity of an evaluatee; publishing information without the evaluatee’s consent could be viewed as treating an evaluatee in an undignified manner. In addition to adhering to the principle of respect for persons, showing compassion toward the subject of the case report is equally important. The author should keep in mind that the subject is a fellow human being who may be experiencing pain, distress, or other suffering.<sup>11</sup> Compassion for the subject could allow for development of a case report that is respectful of the subject as a person, conveys a deeper understanding of the subject’s psychosocial environment, avoids oversimplification or demonizing of the subject, and minimizes “twisting of justice.”<sup>11</sup> By de-identifying a forensic psychiatry case report such that the subject cannot be identified and tailoring it to show a more humanistic side of the subject, an argument can be made that the principle of respect for persons is being upheld. However, we realize that de-identifying a case report alone may not meet some persons’ views of the demand for respect for persons, nor does humanizing the subject necessarily correlate with displaying compassion.

### Liability

Publishing a forensic psychiatry case report without the subject’s written consent could result in legal liability. The medical literature is replete with publications about litigation involving the violation of

confidentiality in case reports where there was a treatment relationship between the authors and the subjects. A review of PubMed and PsychINFO did not reveal articles about litigation and violation of confidentiality involving publication of forensic psychiatry case reports where there was no treatment relationship between the evaluators and evaluatees. A former AAPL Landmark Case, *Doe v. Roe* (1977), highlighted the legal liability that psychiatrists can incur for publishing information about their patients. This case was “a matter of first impression in the United States” (i.e., first case of its kind at the time).<sup>12</sup> In this case, Ms. Doe and her husband were each patients of Dr. Roe (a psychiatrist) for many years. Dr. Roe and her husband, a psychologist, published a book about Ms. Doe and her husband eight years after the termination of treatment. This book reported “verbatim and extensively the patients’ thoughts, feelings, and emotions, their sexual and other fantasies and biographies, their most intimate personal relationships and the disintegration of their marriage.” Ms. Doe found out about the book and brought a course of action seeking an injunction against publication and damages for breach of privacy. The Roes, in defense, claimed the following:

The plaintiff provided verbal consent.

The plaintiff’s identity was concealed.

The plaintiff had no cause for action, given that right to privacy protected only against government intrusions.

The book was of significant scientific value that its contribution to the profession outweighed the plaintiff’s right of nondisclosure.

The plaintiff was guilty of laches in bringing this action.

The defendants’ right to publication was protected by the First Amendment to the U.S. Constitution.

Among several other rulings, the New York County Supreme Court held that a physician who enters an agreement with a patient to provide medical attention implicitly covenants to keep in confidence all disclosures made by the patient concerning the patient’s physical or mental condition, as well as all matters discovered by the physician in the examination or treatment. This is true for the psychiatric relationship. In the dynamics of psychotherapy, the

patient is called to discuss in a candid and frank manner the most intimate and disturbing material.<sup>12</sup>

However, one major distinction between forensic case reports and the case report involved in *Doe v. Roe* is that forensic evaluators inform evaluatees that there is no typical doctor–patient relationship (treatment relationship) established during the course of the forensic evaluation.<sup>13</sup> Although there is no typical treatment relationship established, an argument can be made that there is a doctor–evaluatee relationship that must be respected so that the disclosure of information that is obtained during the evaluation is appropriately regulated. There is no absolute “covenant” to keep confidential all disclosures made by the evaluatee during the course of the evaluation compared with a treatment setting; however, we do not open the proverbial floodgates and let the information flow into the public domain, as forensic evaluators still maintain an ethics-related responsibility to “do no harm.” The relationship of the evaluator to the evaluatee is not a traditional doctor–patient relationship, but it continues to be constrained by traditional principles of ethics governing professionalism in medicine.<sup>14</sup> For that reason, the disclosure of the information that is obtained during the course of the evaluation is restricted. Another difference is that in *Doe v. Roe*, the medium used to disclose information in this legal case was a book. Although there is an altruistic motive in writing books (e.g., furthering the knowledge in the field of study), there is an inherent financial motive when writing a book. Many, if not all journals, do not financially compensate an author for publication of a case report. However, it may be argued that publishing a forensic psychiatry case report potentially rewards the author in other ways, such as furthering an academic career or increasing his or her professional recognition, which may result in more referrals to do forensic cases.

### De-identification

A review of PubMed and PsychINFO did not reveal a universal approach to de-identifying forensic psychiatry case reports. There are obvious identifiers that should not be included: name and initials, photographic images of the subject, addresses, social security numbers, date of birth, and date of death. Additional identifiers which should be omitted include financial information, employment information, electronic mail addresses, medical record numbers, driver license numbers, vehicle identification

numbers, or any other unique material that can identify the subject. Past psychiatric, substance use, medical, and psychosocial histories would need to be sifted to eliminate specific information that could easily identify the subject when this information is coalesced for the case report. Although details of the story are vital and “bring concepts and language to light that clarify the scientific and moral relationships inherent in forensic work,” gratuitous and inflammatory material that is irrelevant to the purpose of the case report should be excluded (Ref. 14, p 301). An additional layer of scrutiny is created when writing about the details surrounding criminal behavior or the allegations in a civil action. Those details would have to be combed through to ensure that the reader cannot identify the subject based on that information unless that information was in the public domain, such as news reports, judicial indexes, and reports that were submitted to the court and later entered into evidence. Because of the difficulties in de-identification, we believe that high-profile forensic cases that are the subject of a significant degree of media attention and scrutiny should not be the basis for a case report, unless all information contained in the case report is available in the public domain. However, if all information is publically available, it would likely lessen the value of a published case report.

In addition to the potentially identifying information that should be excluded in a forensic psychiatry case report, we must note that there is a core set of information, sometimes involving the intimate thoughts and actions of the evaluatee, which may be crucial to the value of the case report itself. For example, in the case involving *pseudologia fantastica*, to illustrate that the deceptions typically involve a kernel of truth, it would be impossible to have illustrated this phenomenon without publishing the actual deception as reported by the defendant as well as the degree of truth at the core of the deception that was confirmed by collateral sources. Without this information, including thoughts expressed directly by the evaluatee, the case report would be meaningless as an illustrative and educational tool.

### Conclusion

Publishing a forensic case report without an evaluatee's consent is not without controversy. Whenever

feasible, we recommend that authors obtain consent from the subject of a forensic psychiatry case report before publication. However, we are also aware from our own personal experiences that obtaining consent is not always practical or possible. In those situations, instead of a universal rule requiring informed consent for all forensic psychiatry case reports, we believe a viable solution would be to look at the case reports on a case-by-case basis. When permission cannot be obtained and the information from the case report furthers significant scholarly discourse and illustrates important dimensions of the case, careful attention to the removal of potentially identifying data, as well as information not necessary to the value of the case report may be sufficient to allow for consideration of publication.

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