Case Studies: Strategies to Protect Patient Privacy
Marla J. De Jong

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Case studies are a distillation of real-world patients or patient care situations. Nurse and medical editors publish case reports to disseminate clinically important information, inform clinicians about lessons learned, add new data to the literature, and generate research questions or hypotheses. Through case reports, authors describe a unique or previously undescribed disease or syndrome, shed new light on the pathogenesis of a disease, describe a novel diagnostic procedure or treatment, elucidate a new or unexpected casual relationship between two diseases, describe an unexpected variation or outcome in the usual pattern of a disease, refute a myth, describe an unlabeled use of a medication, report a new drug reaction or interaction, or describe various other patient care situations (Cohen 2006; Fraser 2008; http://casereports.bmj.com/site/about/guidelines.xhtml#whatcases).

By their nature, case reports are educational and permit medical professionals to learn from their colleagues’ experiences. The educational value of case reports, however, must be weighed against the risk to the patient’s privacy and the serious consequences that may result from inappropriate disclosure. In this paper, I recommend fundamental strategies that enable authors to share seminal information yet uphold patient rights and adhere to ethical guidelines.

Define purpose
Define the purpose of the case study and determine the level of detail needed to be instructive or make your point. For example, when the goal is to inform clinicians about a new syndrome, describe patient and family history, clinical presentation, results of diagnostic tests and procedures, and course of treatment and the patient’s response to it. Sufficient detail is useful to readers who may encounter a similar patient. Conversely, condense patient-specific information when the aim is to identify a research gap or propose new research.

Consider context
Consider the extent to which context provides explanatory value to the case study. In some cases, the time period or patient’s gender, ethnicity, marital status, occupation, or city of residence may illuminate the case, adding to its merit, facilitating learning, and permitting the medical community to make conclusions or pursue further study or research. When, for instance, describing a new constellation of respiratory symptoms, report vital contextual information, such as the patients were New York City firefighters who worked at Ground Zero for much of September 2001. However, withhold superfluous information that is immaterial to the case and may threaten patient privacy. It is likely unnecessary, for example, to mention that a military member who suffered a unique combat injury is the father of quintuplets. Few military members are parents of quintuplets, making it
relatively easy to positively identify the patient.

**Confirm facts**
Confirm facts to preserve the fidelity of the case study. Although usually necessary to disguise the identity of patients, fulfill ethical responsibilities to truthfully report the facts, circumstances, and intangible qualities of the actual case event. Take time to substantiate information, which mitigates any temptation to embellish or manipulate the facts or present imprecise information, which may confuse the reader.

**Protect sensitive information**
Protect sensitive information when gathering information about the original case event. Data compilation is a particularly vulnerable phase of an author’s work. Perhaps a greater risk than ever due to the ease with which data can be accessed, stored, and shared electronically, take deliberate precautions to prevent its inadvertent disclosure. Carefully follow the United States Health Insurance Portability and Accountability Act of 1996 and institutional policies and procedures for how to gain authorized access to identifiable and de-identified data, encrypt data and/or use password protected files, share data with colleagues, store data on an external hard drive or personal computer, and, if required, secure employer approval to submit the case for publication.

**Remove identifying information**
Remove identifying information, realizing that this may diminish the accuracy and overall quality of the case study and value to the reader. Use a balanced approach when deciding what information to de-identify and what to omit. Eliminate all patient identifiers from photographs, video clips, radiographs, or other figures that supplement the text of the case study, unless the patient consents to publish the image. Rather than merely blacking out or cropping photographs to hide identifiable features, consider using methods that not only limit the ability to recognize the patient but also maintain relevant details of the photo without distortion. Eradicate any hidden data or links to other electronic spreadsheets or databases before submitting an electronic file to the editor.

**Obtain consent/permission from the patient/family**
Review Institutional Review Board, institutional, and author guidelines regarding requirements to obtain consent from a patient who is mentioned in the case study. In general, obtain consent from a living person who could be identified from the information published in the case study. If consent cannot be obtained, remove any information so that no one can positively identify the patient. As a matter of courtesy, obtain consent from a relative when the patient is no longer living.

**Avoid publication**
Avoid publication of a case study if it is likely to induce untoward effects or discrimination towards a patient, group, or population. It may be difficult, for example, to disguise the identity of an ethnic group in a rural area that is found to be prone to a life-threatening genetic disorder. Consider refraining from publishing such information as it may be detrimental to patients’ employment or insurability.

In summary, case studies are a valuable addition to the literature, either as stand-alone papers or embedded within a clinical paper. Publication of case studies reflects an author's commitment to improve practice and educate colleagues about important clinical lessons. Application of the above strategies will also protect patients.

**References**

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Author

Marla J. De Jong, PhD, RN, CCNS, FAAN, is Colonel and Dean, United States Air Force School of Aerospace Medicine, Wright-Patterson AFB, Ohio, USA.
E-mail: marla.dejong@us.af.mil, mdejong@aol.com

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