

# The Balance of Truth-Telling and Respect for Confidentiality: The Ethics of Case Reports

*Every patient you see is a lesson in much more than the malady from which he suffers.*  
William Osler, *Aquanimatas*



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**M**edical case reports are as old as the healing profession itself.<sup>1</sup> These ancient medical stories have a modern definition: “A case report is a narrative that describes, for medical, scientific or educational purposes, a medical problem experienced by one or more patients.”<sup>2</sup> Case report experts describe the 3-fold purposes of this type of research: as a mainstay of education; a harbinger of emerging illnesses; and an appraiser of new interventions. Case-based education has long been a pillar of health professions education: Nurses, doctors, and allied health professionals are taught and learn through reading and discussing with their teachers and each other about cases of their own patients and of those in the literature.<sup>3</sup> Case reports also have helped identify and raise awareness of new diseases and rare conditions, such as HIV.<sup>4</sup> Finally, case reports have alerted regulatory agencies and the medical community about medication adverse effects, such as birth defects from thalidomide.<sup>5</sup>

Case reports also have been criticized on both scientific and ethical grounds. Critics argue that many case reports often lack the rigor and consistency of other types of research.<sup>6</sup> Three recent trends in medical publication have strengthened the validity of these criticisms: the increase in the popularity of case reports; the corresponding increase in submissions to journals, including *Federal Practitioner*; and the rise of predatory publishers.<sup>7,8</sup>

The ethical scrutiny of case reports discussed in this column focuses on the tension between providing readers with adequate, accurate information to fulfil the goals of case reports while also protecting patient confidentiality. The latter issue during most of the history of medicine was not considered by health care professionals when the prevailing paternalism supported a professional-oriented approach to health care. The rise of bioethics in the 1960s and 1970s began the shift toward patient autonomy in

medical decision making and patient rights to control their protected health information that rendered case reports ethically problematic.

To address both changes in ethical standards and scientific limitations, a committee of clinicians, researchers, and journal editors formed the Case Report (CARE) group.<sup>2,8</sup> The group undertook an effort to improve the quality of case reports. From 2011 to 2012, they developed the CARE guidelines for clinical case reporting. The guidance took the form of a Statement and Checklist presented at the 2013 International Congress on Peer Review and Biomedical Publication. Since their presentation, multiple prestigious medical journals in many countries have implemented these recommendations.

As part of an overall effort to raise the ethical caliber of our own journal, *Federal Practitioner* will begin to implement the CARE guidelines for case reports for all future submissions. Use of the CARE recommendations will help prospective authors enhance the scientific value and ethical caliber of case reports submitted to the journal as well as assist the *Federal Practitioner* editorial team, editorial board, and peer reviewers to evaluate submissions more judiciously.

An essential part of the CARE guidelines is that the patient who is the subject of the case report provide informed consent for the publication of their personal narrative. The CARE group considers this an “ethical duty” of authors and editors alike. In “exceptional circumstances” such as if the patient is a minor or permanently incapacitated, a guardian or relative may grant consent. In the rare event that even with exhaustive attempts, if informed consent cannot be obtained from a patient or their representative, then the authors of the case report must submit a statement to this effect.<sup>4</sup> Some journals may require that the authors obtain the approval of an institutional review

board or the permission of an ethics or other institutional committee or a privacy officer.<sup>2</sup>

Requesting the patient's consent is an extension of the shared decision making that is now a best practice in clinical care into the arena of research, making the patient or their representative a partner in the work. Ethicists have recommended inviting patients or relatives to read a draft of the case report and agree to its publication or request specific modifications to the manuscript. The CARE group rightly points out that with the rise of open notes in medical documentation, patients increasingly have access to their charts in near or real time.<sup>2</sup> Gone are the days of Sir William Osler when only doctors read medical journals and all of these technical developments as well as standards of research and social changes in the practitioner-patient relationship make it imperative that writers and editors join together to make case reports more transparent, accurate, and consistent.<sup>7</sup>

An additional step to protect patient privacy is the requirement that authors either de-identify potentially identifiable health information, such as age, birth, death, admission, and discharge dates, or in some instances obtain separate consent for the release of that protected data.<sup>8</sup> These restrictions constitute a challenge to case report authors who in some instances may consider these same facts critical to the integrity of the case presentation that have made some scholars doubt their continued viability. After all, the contribution of the case to the medical literature often lies in its very particularity. Conversely, no matter how frustrated we might become during writing a case report, we would not want to see our own protected health information or that of our family on a website or in print without our knowledge or approval. Indeed, the International Committee of Medical Journal Editors states that "If identifying characteristics are de-identified, authors should provide assurance, and editors should so note, that such changes do not distort scientific meaning."<sup>9</sup>

However, the exponential growth of the internet, the spread of social media, and the ubiquity of a plethora of electronic devices, which prior generations of writers and readers could not even imagine, make these limitations necessary to protect patient privacy and the public's trust in health care professionals. The CARE guidelines can help authors of case reports hone the art of anonymizing the protected health information of subjects of case reports, such as ethnicity and occupation, while accurately conveying the clinical specifics of the case that make it valuable to students and colleagues.

We at *Federal Practitioner* recognize there is a real tension between truth-telling in case report publication and respect for patient confidentiality that will never be perfectly achieved, but is one that is important for medical knowledge, making it worthy of the continuous efforts of authors and editors to negotiate.

#### Disclaimer

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