

## Publication of case reports: Is consent required?

Elaine Gibson LLB LLM

Case reports in medicine are fundamentally individual patient stories generally describing unique or unexpected findings in terms of disease or treatment. Anecdotally based, they are considered to be less rigorous an evidentiary base than other types of research. As described by Jenicek (1), although case reports rank low on the scale of types of evidence to be relied on, they are highly important in their frequent role as the “first line of evidence”. Historically, case reports were published without consent of the patient. However, standards have been evolving in law and ethics such that consent should now be viewed as mandatory. The remainder of the present commentary provides justification for this assertion.

The interests at stake include, on the one hand, confidentiality and autonomy and, on the other hand, the need for scientific advancement, described by Levine and Stagno (2) as “pedagogical freedom”. Since at least Hippocrates’ era, patients have been seen to be entitled to respect for the confidentiality of their personal health information (3). The elemental value of confidentiality is rooted in the need for absolute trust by patients that revelations of personal matters to health care providers will not be indiscriminately broadcasted. Furthermore, the right of the individual to choose among treatment options has been enshrined in the concept of ‘informed consent.’ Its roots may be found in the right to respect for autonomy, and the right to determine the course of treatment may be extended to the right to determine what may be done with personal information that is garnered along the way.

There is also, however, great interest in scientific advancement, which has led to some reluctance to seek patient consent to publication of case reports for fear that a negative decision would result in a lack of opportunity to publicize new information that has been gained by a particular case. Psychiatrists, in particular, have voiced concern that patients may not consent due to the nature of their illness – Munchausen’s syndrome being emblematic of this concern (2,4). Thus, there are legitimate interests on both sides of this issue. However, arguably, confidentiality and autonomy are taking precedence in ethics and in law.

Confidentiality is protected through federal and provincial legislation regarding information generally and health information specifically (5-7). Such legislation would

require, at the least, that case reports not contain any identifiable information about a patient without the patient’s consent. Likewise, a number of medical journals have enshrined the protection of confidentiality into their guidelines for publication. The International Committee of Medical Journal Editors (8) requires informed consent for publication if identifiable information is to be used, but does not refer specifically to case reports. This is similar to the approach of the *Paediatrics & Child Health* journal (9).

Following legal advice, the *British Journal of Psychiatry* (10) has adopted a guideline saying that consent must be obtained if an individual patient is described; if consent cannot be obtained, “the report can be published only if all details that would enable any reader (including the individual or anyone else) to identify the person are omitted”. It is important to note that, particularly for case reports in our digital age, the bar may actually be quite high under these laws and guidelines. Case reports often deal with a rare disease or constellation of characteristics and, therefore, a person may be identifiable even if no direct identifiers are mentioned. Furthermore, the prospect of identifiability has increased due to broader access to the case reports themselves, both by professionals and by the public more generally, through medical journals that previously had a circumscribed distribution range, but are now available online. This, combined with the fact that patients are being urged to access health information both online and through libraries, increases the likelihood that case reports will be viewed and individuals may be identified.

Confidentiality is the obligation of third parties to guard the secrecy of personal information; informational privacy refers to the person or group’s entitlement to make decisions regarding uses of the information. Even if there is no reasonable prospect that the individual patient would be identified, autonomy and privacy interests are at stake. As stated above, autonomy is the underpinning for the doctrine of informed consent. The Supreme Court of Canada signalled a dramatic shift in the ‘doctor knows best’ phenomenon when it ruled that patients are entitled to make their own decisions (11). Privacy, with its concomitant right to make decisions regarding the use of one’s information, engages the autonomy interest even if identifiability is not of concern (12).

Health Law Institute, Dalhousie University, Halifax, Nova Scotia

Correspondence: Professor Elaine Gibson, Health Law Institute, Dalhousie University, 6061 University Avenue, Halifax, Nova Scotia B3H 4H9.

Telephone 902-494-6882, fax 902-494-1316, e-mail [elaine.gibson@dal.ca](mailto:elaine.gibson@dal.ca)

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There is a consensus in Canadian law that personal health information is “fundamentally one’s own” (13), and that individuals should, in most circumstances, be the ones deciding how the information should be used. It might be argued, therefore, that case reports, even without any identifiable information, cannot be published without consent (but it must be noted that this has not been addressed by any Canadian court). Indeed, this is the position taken by the *Journal of Medical Case Reports* (14), which has adopted a blanket requirement of informed consent before publication. In the case of

immature minors and those unable to provide consent, consent is required from the parents or guardians. No case report is to be published in the absence of consent. It is notable that this *Journal*, which exclusively deals with case reports, has taken this strong stance in favour of informed consent.

This takes us to the bottom line. Consent is certainly required under a confidentiality analysis for the publication of case reports that contain any identifiable information. Consent is arguably required under an autonomy analysis for all case reports.

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