

## (1.1) Patient consent for case reports

During a clinical read-out, you review an MRI examination that demonstrates key imaging findings in a patient with an extremely rare congenital dysplasia. The limited number of reported cases of this condition indicates a clustering of patients among a small number of families living within a given geographic area. The resident who participated in the read-out expresses an interest in writing up the details of the case, including representative MRI images, as a case report to submit to a popular imaging journal. You recall the educational value of preparing several case reports back when you were a resident yourself and feel that this may be a good opportunity to mentor a resident in a similar experience. In addition, your local institutional review board provides a waiver of the requirement for written informed consent for retrospective case summaries of this nature. At this stage, you feel that you've appropriately laid the groundwork to proceed in working with the resident in the preparation and submission of the case report. However, what additional ethical and professional issues exist related to the potential case report? Are there further actions to consider prior to proceeding with the work?

### Commentary

Case reports have historically played a large role in the radiology literature, often serving as an effective means of sharing unusual yet instructive cases with the radiology community as well as a mechanism for introducing trainees to the process of manuscript preparation. However, more recently, biomedical journals have begun to exercise a greater degree of caution in the publication of cases reports. Namely, various aspects of case reports raise a distinct possibility of violating patient confidentiality, even if the manuscript does not overtly disclose the patient's identity. First, it may be possible to readily identify the patient being presented given that case reports often disclose extensive and detailed information regarding an individual patient, including demographics, medical history, laboratory and imaging results, interventions, and outcomes[1]. In addition, the authors and institution originally caring for the patient can generally be deduced from the article meta-data. Moreover, given that case reports typically present a rare or unusual diagnosis, the diagnosis itself, in some circumstances, may be sufficient to identify the patient. Such factors create circumstances in which an individual may recognize a case report as presenting his or her own care or the care of a friend, colleague, or family member. The Internet has enhanced the ease with which individuals' are able to readily find such articles, with increasing reports of patients recognizing their own identity within case reports. Such occurrences also may also serve as the basis of lawsuits. For instance, one case report of a patient with bulimia nervosa published in the *British Journal of Psychiatry* led to a lawsuit from the patient when her friend recognized her as the subject of the report given the specificity of its content (i.e., the patient's demographics, profession, and other personal characteristics) [2].

Given these considerations, it cannot be presumed that an anonymously written case report sufficiently protects patient confidentiality. Even if the drafting of the case report is in compliance with one's local institutional review board, additional precautions are warranted. An increasing number of journals are requiring that authors obtain a written letter from the patient who is the subject of any report with potentially identifiable patient information, indicating that he or she has read the manuscript and approves of its submission, with the patient's permission potentially being cited in either the Methods or Acknowledgments section of the article. One journal requests that the authors maintain the written consent signed by the patient and rather send to the journal a separate statement that such consent has been obtained, so as not to disclose

the patient's identify to the journal itself [3]. A different journal requests that the patient be given an opportunity to submit a description of the case from his or her own perspective for inclusion with the article [4]. While authors need to check the policies of the given journal and ensure that their case report is in compliance, they may choose to seek the patient's permission (or that of the parent or legal guardian for pediatric patients), even if this authorization isn't formally required by the given journal. Indeed, a patient who is unhappy in learning that he or she is the subject of a case report is unlikely to be satisfied simply on the basis of being informed that the publishing journal and local IRB did not require written permission. In this regard, receiving the patient's permission can help avoid any negative repercussion should the patient later discover the published report and deem it to constitute a violation of privacy or become dissatisfied with their prior care based on new insights learned from the report.

When preparing the case report, authors should consider leaving out or reporting in a more general fashion details that are not needed for communicating the important aspects of the case. For instance, the patient's specific age, ethnicity, and/or occupation may be irrelevant for the aim of a given case report. The risk that any given detail from the case will contribute to revealing the patient's identify will vary based on the uniqueness of the given item (i.e., a past medical history of an exceedingly common condition such as hypertension vs. a history of a highly rare congenital syndrome associated with families from a specific city). In addition, as with any article, authors and journal staff must ensure that all images are cropped to exclude the patient's name, account number, date of birth, as well as other protected health information. Ultimately, even if preparing the case report in sufficiently general terms that not even the patient recognizes their own identity, it may still be appropriate to seek consent out of respect for the patient's control over their own health information [5]. For instance, the Journal of Medical Case Reports strictly requires written informed consent from the patient for all submitted case reports, regardless of other considerations [4]. When sharing the manuscript draft with the patient in the process of obtaining consent, authors should be sensitive to possible emotional reactions by the patient in response to reading the material that describes their own diagnosis and medical care.

In the present case, you are considering preparing a case report that describes a highly rare condition associated with a specific patient population. While efforts should be taken to de-identify the report to the extent possible, it is questionable whether the manuscript can be sufficiently de-identified to remove any possibility of disclosing the patient's identity. In this circumstance, you should consult with the journal to which you are considering submitting the work to learn the journal's policy regarding patient authorization for such reports. Even if the particular journal does not require receiving the patient's permission, you are still strongly advised to provide the patient with a draft of the manuscript, receiving the patient's written permission for its submission, and maintaining this permission within your own records. This approach respects the patient's control over his case and protects yourself in the event that the patient later recognizes himself in the published report.

## References

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