Academic medical journals that publish clinical studies or case reports may contain images from individual patients. In many cases, such as photographs, these permit patients to be identified. Twenty years ago, medical journals were available only in academic libraries, but nowadays almost all academic journals are available online and many use an open-access model of publishing, which means that the content is freely available. The use of licences such as the Creative Commons system (which is promoted by researchers, funders, policy makers and patient groups) also permits reuse of material, including images, on any other platform, which might include republication of patient photographs in a totally different context [1]. For example, the CCBY licence allows anybody to reuse an image without permission, and for any purpose, so long as the source is acknowledged. Although clinicians and patients increasingly use the Internet to search for medical information, it is not clear whether they are aware of the fact that, once published under a CCBY licence (unlike under traditional copyright laws), the reuse of a clinical photograph cannot be controlled. Although patients still have a high level of confidence in health professionals, the patient-doctor relationship has shifted from a paternalistic to a shared-decision model, in which health professionals have responsibility to provide the best information to patients to permit them to make an informed choice. This applies not only to treatment choices, but also to participation in research, and to the publication of individual photographs. Therefore, journals should have clear policies and provide guidance for authors to respect essential ethical principles to preserve patients’ privacy, confidentiality and anonymity, and editors should make sure that those policies are implemented. Patients’ consent for the publication of any individual images should be given freely and be based on appropriate information about how the images may be used. In addition, authors and editors must follow legal requirements such as the recently implemented EU directive (GDPR) requiring strict patient data protection.

Although patient confidentiality is an important principle of medical and publication ethics, many journals provide little or no guidance to authors on this, and few appear to have clear policies. Recent studies that have analysed publishing practices on this issue have found important inconsistencies among journals regarding written consent for publishing identifiable patient photographs [2,3]. In many cases there appear to be no guidelines about how clinicians should obtain consent from patients for the publication of their photographs. According to current ethical guidelines [4], individual patient data and information (as opposed to aggregate data, such as that from clinical trials) should be published only if there is a valuable reason. Ever since clinical photographs have been published, authors and editors have made efforts to develop techniques to reduce the chance of patients being identified and thus to preserve patient privacy. This is particularly problematic for photographs involving the facial region. The most widely used technique is to print a black bar over the eyes or, more recently, to blur or pixelate the eye area. Although these techniques continue to be used, they are widely recognized as insufficient as they cannot ensure anonymity. We have studied patients’ and health professionals’ opinions on the publication of facial photographs in academic journals. Our study found that both doctors and patients were more likely to agree with the publication of facial photographs with covered or blurred eye areas [5]. Regardless of whether facial photographs are de-identified or not, written informed consent for publication must be obtained from the patient [4]. Some journals (e.g. The Lancet) advise that de-identification is not necessary if informed consent has been obtained appropriately. However, our study in Croatia showed that health professionals and students of medicine and dentistry lacked knowledge about the about importance of obtaining written informed consent in all cases before the publication of individual patient photographs [5].

The publication of individual patient images or data should be allowed only if the consent process has been conducted properly. This usually means that patients have provided written consent for publication. This consent should normally be separate from any consent for treatment or for participation in research. Ideally, patients should be allowed to read the manuscript and should receive information about the context of the photographs (and their possible reuse) before they give approval. However, there may be practical difficulties in providing patients with a manuscript, for example if they do not understand the language of publication (e.g. English), in the case of children or those who are unable to make decisions for themselves or if they have difficulties in following the highly technical language of scientific papers. Because of these difficulties, there is a need for clear guidelines on this issue. Many academic journals cite publishers’ policies for publishing individual patient data, or refer to the ICMJE guidelines [4]. Furthermore, some journals (e.g. BMJ journal group) provide their own consent form for publishing patient photographs. Following best current practices, Case Reports in Women’s Health in its Instructions to Authors clearly states “Appropriate consents, permissions and releases must be obtained where an author wishes to include case details or other personal information or images of patients and any other individuals in an Elsevier publication”.

Although many journal websites emphasize the importance of obtaining written patient consent and clearly state that masking the eyes is not sufficient to preserve patient privacy, detailed guidance on best practices for obtaining consent under various circumstances is
lacking. Furthermore, even when journals state that consent must be obtained, our study found that such information is often missing from publications.

Our research suggests that appreciation of the importance of obtaining written informed consent for the publication of individual photographs is often lacking on the part of both health professionals and patients. This suggests a role for journals in providing clear guidance, and for academic institutions to provide education and training. It is important that current policies and practices on the publication of individual patient information, such as photographs, in academic journals should be strengthened to protect patients’ rights to privacy and confidentiality.

Contributors

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