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Patients are entitled to privacy – also in medical journals

Why did you write about me without asking first?

Recently, a patient contacted the Journal of the Norwegian Medical Association to «(...) complain that he could recognise his own medical history in an article». In 1991, Magne Nylenna, who was editor of this journal at that time, started one of his editorials thus (1). Now, unfortunately, we need to reiterate his words. This in itself is bad enough, but in addition to self-recognition, the patient in question had also found some test results that he/she was unaware of. The article contained an analysis of a larger set of patient data, and in the presentation the data had been broken down into too small categories, thus making the patient recognisable.

Around 1990, only ten per cent of the journals had regulations for consent to publication of case histories (1). Nylenna became a driving force in producing better international regulations (1–3). Today, such consent is a matter of course in medical journals. Our guidelines to authors comprise a separate chapter on anonymisation and informed consent (4), and this topic has been discussed in several editorials (5, 6).

In 1991, Nylenna wrote: «As long as the patient is the only one who can recognise him-/herself, this is hardly a major problem» (1). Today, we regard things differently. As a patient, one should not need to risk finding one's own medical history on the Internet without having been asked beforehand. Nylenna's main point persists: Ethical rules must be updated and developed in line with the needs of the time (1).

How could we err in this way? The editors assess all manuscripts with a view to anonymity and informed consent, and this case was no different. In presentations of data sets, total anonymity can often be achieved by merging groups or removing information to eliminate the need for consent. The authors, however, often claim that we are too cautious; for example, we are sometimes told that we are «more Catholic than the Pope». The authors would like to include extra details, with the best intentions – the information may be of interest – but the editors delete such information to preserve the patient's anonymity. In the study in question, the patients had consented to participate, but consent to participation and consent to publication are two different matters (6). In such cases, we need to be especially cautious with regard to the information which is provided. This case may serve as a reminder for us all.

It may therefore appear paradoxical that in this issue of this journal, we present four case histories to which no consent has been provided (7). According to the author, Jan Harald Dobloug, who is the medical officer in an insurance company, his company has in recent years submitted fourteen cases for assessment to the Council for Medical Ethics and seven to the Norwegian Board of Health Supervision. In four cases, the company has failed to gain acceptance of its claim that the doctor had violated the ethical guidelines of the Norwegian Medical Association or the Health Personnel Act. In the

company's opinion, these conclusions by the Council for Medical Ethics and the Norwegian Board of Health Supervision are «highly debatable» (7). These are the four cases that Dobloug presents. The manuscript has caused lengthy discussions between the editors and with the author, and more than eight months have therefore passed from when the article was received until its final publication.

In a recent editorial, medical editor Siri Lunde wrote that the need for consent can be waived if *all* of the following three criteria are met: considerations of public interest outweigh possible harm; it is impossible to obtain consent; and a reasonable individual would be unlikely to object to publication (6). What nevertheless has caused us to publish this article is that the author addresses a topic that we deem to be of major social interest. The rulings by the Council for Medical Ethics and the Norwegian Board of Health Supervision were final, without any opportunity for appeal. We regard the rise of a public debate on such rulings as an important democratic asset. This question is far from new. The ancient Romans expressed it like this: «Quis custodiet ipsos custodes?» – Who guards the guardians? – a précis of a longer passage by the author Juvenal (67–127) (8). Furthermore, this journal has raised such issues also on previous occasions (9).

In the case descriptions in Dobloug's article, several details have been omitted or changed to prevent identification of the patients (7). This violates the prevailing rules established by the Vancouver group, which say that changing factual information, such as gender and age, is not an acceptable method of ensuring anonymity (1, 4). These reformulations are part of the author's and our search for a solution that allows sufficient information to emerge, but no more than what is necessary to convey a medically comprehensible impression of the cases. We believe that we have found an ethically acceptable solution.

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