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Photo: Einar Nilsen

Asking permission to publish a patient's story generates trust. The fear of opening old wounds or being rejected is exaggerated.

## Is it my mother?

A woman in her fifties is admitted to the local hospital with chest pains. She is recently divorced and has two children. In recent years she has been repeatedly admitted for the same reason, and it has been concluded that the pains are related to anxiety. She underwent surgery for appendicitis as a child and is being treated for hypertension, but is otherwise healthy. Her father died from heart disease at a young age.

Chest pains, hypertension, appendicitis – common conditions that cannot possibly be associated with a particular individual when seen separately. But what if they are linked? And when we know that the patient is recently divorced and that her father died at a young age? And that the authors are employed at Sørlandet Hospital Arendal? Will her children recognise her?

Not many years back, such stories were published without the patient's consent (1). The requirements have later been tightened considerably, in this journal as well as internationally (2–4). One of the reasons is the Internet. The time when the Journal of the Norwegian Medical Association was «by doctors – for doctors» has passed. The content is freely available online. Anybody can see it, and we know that anybody does see it: *tidsskriftet.no* has about 8 000 visits daily, many by non-doctors.

Total anonymisation of case histories is difficult or near-impossible (5). This journal therefore requires written consent on a specific form, and the patient must be offered an opportunity to see the finished article before it is published. Even though consent has been provided, all redundant information that may identify the patient should be avoided (6). There is an obvious need for this, and most people would probably agree to such practices. As patients, we should not have to risk finding our own case histories on the Internet without having been asked beforehand.

Consent to publication is relevant not only for the case histories. Individual patients may also be recognised or recognise themselves in small patient samples, irrespective of whether the information has been collected through reviews of patient records or as part of a clinical study. In clinical studies the patient provides informed consent, but consent to participation and consent to publication are two different matters (2). Certainly, the patient has signed a declaration saying that the information can be published in an anonymised form, but will the patient and the researcher have the same idea of what this means?

Imagine a group of 30 people diagnosed with prostate cancer over a specified period of time at Haukeland University Hospital. So far, so good. Table 1 shows co-morbidity and prognosis: Two patients suffered from COPD, one had suffered a stroke and was seriously depressed, and thus ended up in the group with a poor prognosis. Here, matters are taking a difficult turn: How much information is needed before a neighbour or a colleague will recognise you?

The boundaries of identifiability are subtle. There are no definite answers as to what type and how much information can be reported without consent. In principle, nobody should be able to recognise the patient, including the patient him-/herself. This issue keeps recurring when small samples are presented. Most often, requesting consent would be the simplest solution. In other cases, total anonymity can be preserved in the material for example by merging sub-groups.

The case histories, however, are different. Strictly speaking, it would be impossible to maintain the anonymity of the patient to an extent where nobody can recognise him or her. If consent cannot be obtained, publication will generally be out of the question. The Committee on Publication Ethics describes the following exceptions: «... if public interest considerations outweigh possible harms, it is impossible to obtain consent and a reasonable individual would be unlikely to object to publication» (2). In practice, however, meeting all three criteria will rarely be possible. The public interest will rarely be considered as outweighing the harm to the patient, and it will almost never be *totally* impossible to obtain consent.

On the other hand, it is not uncommon for authors to be reluctant to ask. What if the patient refuses? This happens very rarely. If the answer is negative, there will be a reason for it, and this underscores the value of asking. Many authors find it especially difficult to contact the next of kin if the patient has died. Our experience, however, indicates that the fear of opening old wounds tends to be exaggerated. On the contrary, many relatives find it meaningful to be able to help others.

The case histories in this journal are popular and often instructive (7). You can find them in every issue. Two of the columns, Case reports and Images in medicine, are even dedicated to individual patients. The journal maintains strict requirements for consent – «not out of fear of the lawyers, but out of respect for the patients» (5). The requirements are not an obstacle to writing about patients, on the contrary. For us to have the opportunity to learn from individual patients we depend on their trust. Asking permission generates trust.

### References

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