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Questionable ethics – whistle-blowing or tale-telling?

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Abstract

Renal biopsy is a potentially hazardous procedure, generally performed for therapeutic reasons.

An open renal biopsy was performed when there appeared to be no accepted clinical indication and its results published in a specialty journal, whose editors declined publication of subsequent correspondence, questioning the ethical propriety of such a procedure. The implications for clinical practice, authors, editors and readers are discussed.

Introduction

Clinicians, researchers and editors have a moral duty to abide by the ethical codes which govern medical practice. The last half century has seen a shift in focus from physician-centred ethical thinking to a patient-centred approach. This places the interests of patients above those of doctors; researchers, authors and medical editors are not exempt from this responsibility – are readers?

CASE REPORT

In 1995 a journal published a communication reporting the histopathological findings in a patient with an inherited renal-concentrating defect. The patient was 16 years old. Investigations showed no evidence of nephrotic syndrome, renal failure (acute or chronic) and no abnormalities of the urinary sediment, nor was he suffering from some other multisystem disease: these are the indications for renal biopsy proposed in a standard textbook of nephrology.[1] After informed consent was obtained the patient underwent an open renal biopsy. This involves surgical exposure of the kidney so may have involved general anaesthesia. The renal histology was essentially normal except for minor abnormalities in the proximal tubules.

In October 1995 I wrote a letter to the editor of the journal, pointing out that the procedure appeared to lack clinical benefit to the patient, was therefore presumably experimental and the paper seemed not to have been subject to ethical review. The author of the paper replied to the journal editorial department in a letter dated 28 February 1996 and the abbreviated text is given here.

"We performed an open renal biopsy on a 17(*sic*)-year-old patient . . . to evaluate the severity of the renal disorder, because we considered that we should evaluate the prognosis of the disease since we have currently no definitive therapy for this disease, and it often progresses to renal failure.

"Although we have an ethical committee on organ transplantation, . . . we have no ethical committee on receiving clinical examinations. However, we explained the necessity of performing an open renal biopsy to the patient and his parents, and obtained their consent. There was no question on the biopsy from the referees."

The editorial office sent a copy of this to me; I found this explanation unsatisfactory and asked the editors whether they were proposing to publish the correspondence. In a letter dated 19 April 1996 a member of the editorial department wrote declining to publish, maintaining that the editorial decision was final.

COMMENT

This correspondence raises three important questions: medical, editorial and general. First, was the procedure unethical? The procedure satisfied no well established criteria for the performance of a renal biopsy. Although the authors say it was performed because they considered "that we should evaluate the prognosis of the disease" there is nothing in the literature to suggest that renal biopsy findings would help the management of the patient.

The authors suggest that the condition "often progresses to renal failure" but give no reference. There was no indication that this patient had either acute or chronic renal failure. The only clear-cut pre-biopsy abnormality was dilatation of the renal tract, a recognised complication of the primary condition (and which may cause renal insufficiency) but one whose management is not helped by knowledge

Key words

Renal disease; renal biopsy; publishing ethics; research ethics.

of renal histology. Furthermore in their letter the authors say there is no definitive therapy for the renal condition; rather than being an argument for performing a biopsy this supports the case for not doing so – unless it was purely for research.

In both the paper and the letter the authors acknowledge that consent was obtained from patient and parents but do not make it clear whether the consent givers were aware of the purpose of the biopsy, whether it was for therapeutic or non-therapeutic research purposes. In experienced hands percutaneous biopsy has a morbidity and mortality which are acceptable when it is performed for therapeutic reasons. In this case an open biopsy may have carried the additional risk of general anaesthesia. In the UK it is doubtful whether a procedure of this magnitude carried out for non-therapeutic purposes would be acceptable to a research ethics committee.

Renal biopsies are usually reviewed collaboratively by clinicians and histopathologists; this form of audit should bring to light examples of clinical practice which are ethically questionable. Although one would defend in principle the legitimacy of doctors to take unorthodox clinical decisions in exceptional circumstances and with informed patient consent one would also expect those doctors to be accountable for them and to justify their actions. In this case there seems to be neither accountability nor acceptable explanation.

The second point concerns the position taken by the journal's editorial staff and editor. Their ethically correct position should be to decline publication to scientific communications where information was obtained by ethically questionable means. Some might claim that information so obtained was sufficiently valuable to justify the methods used to obtain it. Most, however, would not take that position, regarding the treating of a patient as a means to an end as unethical. Few journals give ethical guidelines in their published instructions for authors, although some ask referees to comment on ethical aspects of submitted manuscripts. Ethically questionable practice might be overlooked by editors and referees – no system is perfect. However, it would seem correct for the editor of a journal to acknowledge that ethically uncertain material had been published – or at least to publish the correspondence so that the matter could receive an airing. Regrettably this was not done. *The Lancet*'s appointment of an independent ombudsman is a welcome and innovative development[2] which should be considered by other journal editors.

The third note concerns the perturbed reader. Having raised the matter and been rebuffed by the editors should that be a signal to desist or should it be pursued – and if so how? Do readers have their own ethical responsibility which should be discharged?

My solution has been to pose the question to the readers of the *Journal of Medical Ethics* but I doubt the journal would flourish if it became the repository for all such ethical whistle-blowing. A further difficulty is that such activities might be seen as anti-science, creating further division in the relationship between science and ethics, which should be closer.

If the medical profession is to retain the high level of public esteem that it now enjoys in most parts of the world the performance and publication of ethically uncertain clinical activities and reports are unwarranted. Such activities are harmful to the patient/doctor relationship and thus to patients.

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References

1 Ponticelli C, Mihatsch MJ, Imbasciati E. Renal biopsy: performance and interpretation. In: Cameron S, Davison AM, Grunfeld JP, Kerr D, Ritz E. *Oxford textbook of clinical nephrology*. Oxford: Oxford University Press, 1992: 143–6.

2 Horton R. *The Lancet*'s ombudsman. *Lancet* 1996; **348:** 6.