Medical records: law, paternalism and harm

The Court of Appeal has, for the first time, recognised a person’s common law right of access to his or her medical records. In *R v Mid Glamorgan Family Health Services Authority, ex parte Martin* (hereafter *Martin*) [1], the court held that a health authority, in common with a private doctor, is under a common law duty to allow a person access to his or her medical records except where, in view of potential detriment as a result of such access, it is not in his or her best interests to do so.

The ruling is welcome for persons seeking access, and clarifies for practitioners and administrators the legal position regarding access to records not covered by legislation. Under the Data Protection Act 1984, as modified [2], and Access to Health Records Act 1990, individuals have rights to see their medical records. However, the former Act applies only to records stored electronically and the latter only to records made on or after 1 November 1991. *Martin* has now clarified the position for manually held records made prior to this date.

None the less, the exception to the rule in terms of best interests and detriment risks permitting a paternalistic and restrictive approach to access, which sits uneasily beside the generous exercise of respect for patient autonomy and widespread principle and medical practice favouring disclosure except in much more narrowly defined circumstances. However, because the decision in *Martin* is permissive rather than prohibitory, doctors need not feel bound by its restrictive approach.

Facts of Martin

Trevor Martin, 45 years old at the time of trial, had, as an adolescent, received psychiatric treatment from doctors employed by what was then the Mid Glamorgan Family Practitioner Committee (now the Mid Glamorgan Family Health Services Authority). Twenty-five years later he wanted to understand his past treatment, in particular a decision to remove a social worker who had been involved in his case and whom he said he had loved. He wanted to move on psychologically and believed that understanding part of his earlier development through examination of his records would help that process.

His initial requests to the relevant health authorities were rejected. He then instructed solicitors, seeking redress through the European Commission on Human Rights. When this proved unproductive he renewed his requests with the South Glamorgan Health Authority, holders of part of his records. These were also refused, on the basis of advice given to the authority by a consultant psychiatrist—who had not seen Mr Martin—that access would be detrimental to him and not in his best interests. Both health authorities claimed an absolute right to control access to medical records subject only to legislation and the rules of the Supreme Court. Mr Martin then issued an application for judicial review, challenging the health authorities’ refusal. Shortly before trial, the health authorities, acknowledging that the consultant did not have first-hand information regarding Mr Martin’s current health, offered to disclose the records to a medical adviser nominated by him in order to determine whether or to what extent disclosure could be made without causing harm. The offer was not accepted by the date of trial.

Judgments

The trial court held that there was no right of access to the records at common law [3]. Although the Court of Appeal dismissed Mr Martin’s appeal, it ruled unanimously that a health authority, in common with a doctor, is under a general duty to grant access except where it would not be in the best interests of the person seeking access, for instance where it would cause detriment to him or her. The court seemed to be influenced by the consultant psychiatrist’s opinion that disclosure would be detrimental to Mr Martin even though he had no first-hand knowledge of the applicant. Thus, a speculative opinion about Mr Martin’s ability to deal with the information in the record was sufficient at first instance to preclude access. The court did not question the basis on which such an opinion could be made. Arguably, such an opinion, without assessment of a patient’s current health or competence, was tantamount to inappropriate paternalism. However, the court further decided that, in any event, it could not be said that the health authority acted unreasonably since it offered Mr Martin the opportunity to nominate an independent medical adviser of his choice to determine whether access would be of detriment to him.

Reliance on ‘best interests’, a legal term employed for adjudicating consent cases involving minor children who are not Gillick-competent [4] and legally incompetent adults [5], may be inappropriate in a case involving a competent person’s request for access to his medical records. The best interests approach,
grounded as it is in the ancient paternalistic legal tradition of *parens patriae* (meaning parent of the country)—whose determination in the *Martin* case is apparently conferred on doctors—risks reinforcing medical paternalism and certainly consolidates medical control over personal health information. It also leaves too amorphous a discretionary power in the hands of the doctor or health authority. Many courts, conscious of the vague nature of a best interests approach, and mindful of the need to protect patients’ rights from inappropriate exercise of medical authority, have detailed conditions for its exercise [6]. Given these concerns, it is reassuring that a straightforward best interests test is qualified in *Martin* by reference to detriment. However, even this qualification is not without problems.

**Detriment alone: insufficient**

Framing the exception in terms only of detriment to the person seeking the record, seems insufficient protection of that individual’s interests in information of a personal, intimate and potentially beneficial nature. Detriment can mean many things. Since doctors need clear guidance on the law, is reference to detriment alone sufficient? Would a doctor be failing in his obligation to disclose by withholding information in the record because the patient might be upset as a result? What if the disclosure would contribute to a usually equitable patient feeling depressed? While general rules may be helpful, in the case of medical records—where issues of autonomy, harm and quality of care are at stake—the exception regarding detriment may be considered to be too vague.

This seems to be acknowledged in many Commonwealth and American cases which have defined exceptions to general rules on disclosure of information prior to a medical procedure. In the leading American case on information disclosure, the court stated that a doctor was exempted from the obligation of disclosure where disclosure

‘poses such a threat of detriment to the patient as to become unfeasible or contraindicated from a medical point of view. It is recognised that patients may become so emotionally distraught on disclosure as to foreclose a rational decision, or complicate or hinder treatment, or perhaps even pose psychological damage to the patient. Where that is so, the courts have generally held that the physician is armed with a privilege to keep the information from the patient, and we think it clear that *portents of that type* may justify the physician in action he deems medically warranted [7].’

Here, detriment alone was insufficient to justify nondisclosure. There had to be harm of the type envisaged by the court. Similarly, in one of the leading Australian cases on information disclosure the court stated that a doctor is justified in withholding information

‘when he judges on reasonable grounds that the patient’s health, physical or mental, might be seriously harmed by the information.’

Here the court imposes two qualifications on the prospect of harm. First, that there must be reasonable grounds for establishing such a claim and, secondly, that the harm must be serious.

That the exception regarding detriment seems to be insufficient is reinforced by reference to relevant British legislation. In the Access to Health Records Act 1990, which establishes a general right of access to health records, access shall not be given where, in the opinion of the record holder, information is ‘likely to cause serious harm to the physical or mental health of the patient... [9].’

This makes clear the gravity of harm and its likelihood. Identical wording exists in the relevant provisions exempting disclosure under the Data Protection legislation and Access to Medical Reports Act 1988, though the 1988 Act vests decision-making authority in the medical practitioner and the Data Protection regulations leave the determination objective. These substantive criteria reflect the fact that the purpose of the legislation, which is to protect a patient’s right of access to health records, ought not to be circumscribed too easily. Such an aim seems to be reflected in the policy of one American psychiatric clinic which states that

‘patient access... should be permitted unless it is determined that such access would cause an imminent, substantial, and concrete detriment to the patient’s well-being. Only under these circumstances should access be denied [10].’

Similar considerations should arguably apply to a doctor’s or health authority’s exercise of the common law duty to grant access.

**Assessing detriment**

Studies on detriment to a patient as a result of access show less prevalence of harm than traditional assumptions suggest [11]. They displace the assumption that all detriment is the same or irreparably harmful. A range of emotional responses is shown, including no evidence of detriment [12]. Those that report what might be regarded as hurt emotions reveal a range of responses. In one study of 95 patients of a general practice in London who were given access to their notes, 10% of respondents stated that they had been ‘upset’ by reading them. This upset included six patients’ recollections of ‘bad times’ in the past, one patient’s sense of unfair criticism at seeing a doctor’s comments about her lacking insight, one patient’s sense that a note was untrue, and another’s feeling of sadness. However, the authors note that although these patients were upset about particular issues they did feel that record-sharing was reassuring, informative and helpful [13]. The one study which reports an angry reaction from 10 of 27 patients who had
requested access to their records, who seemed anyway to be in serious conflict with the hospital staff. The study also found that an additional group of eight patients of those who were particularly worried about their prognosis tended to be reassured by the opportunity to review their charts [14].

Most studies show that access tends to reduce patients’ anxiety [15], consistent with most reports on written disclosure of personal health information [16]. It has also been argued that refusing patients access to their records or otherwise withholding information may be as detrimental or more detrimental, than disclosure [17]. Moreover, in line with the approach that discussion of potentially harmful matters may be part of the therapeutic process [18], it has been noted by doctors in one general practice that the cases in which a patient is too unwell psychologically to deal with information are rare, and that sometimes the extremely anxious patient is helped by access to a frank discussion of all that is in the medical record [19].

Yet, even in those studies whose authors advocate a move away from paternalistic practice, there remains a residual paternalism regarding the matters which doctors believe may cause anxiety to patients. This is understandable, given the traditional discourse on beneficence and non-maleficence in medical education and practice. However, to the extent that these studies seem to suggest that anxiety is to be avoided at all costs, they may underestimate the patients’ ability to deal with the information without anxiety or to work through this anxiety on their own terms. For instance, in a study of 100 patients given copies of their problem cards, one general practitioner states that a major benefit is the increased autonomy that such sharing can give a patient—yet he withheld information in circumstances such as the case of an elderly person who was thought unable to comprehend the meaning of the term ‘brain atrophy’, and so might be made unduly anxious [20]. Conceivably, communicating the nature of this condition at the elderly person’s intellectual level could have solved that difficulty. By avoiding discussion of this condition, the doctor may have deprived the opportunity better to confront the prospect of death and to settle her affairs, if any, before the brain atrophy affected lucidity. It has been suggested that part of the profession’s objection to access might be because doctors are afraid of handling the consequences of disclosure [21]. This could be particularly apposite where patient detriment, particularly anxiety about death, is envisaged. If so, doctors might be seen to be abdicating their responsibilities to show care and compassion towards their patients.

**Detriment and generosity**

For patients whose records are not stored electronically, and hence are not subject to the Data Protection legislation, or made after 1 November 1991, and hence not subject to the Access to Health Records Act 1990, the *Martin* case now establishes the general circumstances in which a patient is entitled to access. This is a welcome clarification of the law. However, to the extent that the decision frames patients’ entitlement in terms of best interests, it risks reinforcing medical paternalism. The qualification to the best interests approach in terms of detriment to the patient seems insufficient when compared to analogous laws, medical practice and studies on patients’ access to records. It might be preferable to justify nondisclosure only where it would be likely to cause serious harm to the person which could not be avoided by counselling.

Since the decision in *Martin* is permissive rather than prohibitory, doctors have an opportunity to interpret its meaning generously—in a way that seeks to enhance patients’ autonomy, affirm their interest in personal health information, and respect their capacity to work through information which might, from a paternalistic view, seem too detrimental to disclose. This calls for a spirit of generosity. It entails a close judgment—as any law ought to require—but it also asks what no law can enforce: an exercise in insight and strength regarding each doctor’s own ability to communicate and counsel clearly, respectfully and with compassion.

**References**

1. R v Mid Glamorgan Family Health Services Authority, ex parte Martin [1995] 1 WLR 110.
2. The Data Protection (Subject Access Modification) (Health) Order 1987 (SI 1987, No. 1903).
3. The Times, 2 June 1993 (law report on: R Mid Glamorgan FHSA, expt Martin).
4. R (A Minor) (Wardship: Consent to Treatment) [1992] Fam 11.
5. R v F (Mental Patient: Sterilisation) [1990] 2 AC 1, and Airedale NHS Trust v Bland [1993] 2 WLR 316.
6. Conservatorship of Valerie N.707 P 2d 760 (Cal, 1985), and Re Jane [1989] FLC 92-007 (Aust).
7. Canterbury v Spence 464 F 2d 772 [1972] at 788-9 (author’s emphasis).
8. F v R [1983] 33 SASR 189, at 193 (author’s emphasis).
9. Access to Health Records Act 1990, S5(1)(a) (author’s emphasis). For the equivalent legislation for Northern Ireland see: The Access to Health Records (NI), Order 1993 [SI 1993, No. 1250 (NI4)].
10. Roth LH, Wolfard J, Meisel A. Patient access to records: tonic or poison? Am J Psychiatry 1980;137:592-6.
11. Bernstein RA, Andrews EM, Weaver LA. Physicians’ attitudes towards patients’ requests to read their medical records. Med Care 1981;19:118-21.
12. Golodetz A, Russel A, Raymond M, Milkaus RL. The right to know: giving the patient his medical record. Arch Phys Med Rehab 1976;57:78-81.
13. Baldry M, Cheal C, Fisher B, Gillett M, Huet V, et al. Giving patients their own records in general practice: experience of patients and staff. Br Med J 1986;292:596-8.
14. Altman JH, Reich R, Kelly JJ, Rogers MP. Patients who read their hospital charts. N Engl J Med 1980;302:169-71.
Alcohol and the heart in perspective

SENSIBLE LIMITS REAFFIRMED

Joint report of the Royal Colleges of Physicians, Psychiatrists and General Practitioners

The Royal Colleges of Physicians, Psychiatrists and General Practitioners have all endorsed a graded approach to risks of alcohol consumption which has led to their recommending 'sensible' limits (14 units for women and 21 for men). The question has now arisen as to whether these 'sensible' limits should be relaxed in view of data suggesting that moderate intake of alcohol protects against coronary heart disease. A working group of the three Colleges has therefore reviewed the evidence in the light of data on all-cause mortality, psychosocial risks and on the possibility that recommendations that might lead to an overall increase in alcohol consumption would also increase the number of heavy drinkers. Its conclusions are published in this report.

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